



King's Research Portal

DOI:

[10.1016/j.yebeh.2018.05.044](https://doi.org/10.1016/j.yebeh.2018.05.044)

Document Version

Peer reviewed version

[Link to publication record in King's Research Portal](#)

Citation for published version (APA):

Bruno, E., Simblett, S., Lang, A., Biondi, A., Odoi, C., Schulze-Bonhage, A., ... Richardson, M. P. (2018). Wearable technology in epilepsy: The views of patients, caregivers, and healthcare professionals. *Epilepsy & Behavior*, 85, 141-149. <https://doi.org/10.1016/j.yebeh.2018.05.044>

Citing this paper

Please note that where the full-text provided on King's Research Portal is the Author Accepted Manuscript or Post-Print version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version for pagination, volume/issue, and date of publication details. And where the final published version is provided on the Research Portal, if citing you are again advised to check the publisher's website for any subsequent corrections.

General rights

Copyright and moral rights for the publications made accessible in the Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognize and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the Research Portal

Take down policy

If you believe that this document breaches copyright please contact librarypure@kcl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

Wearable technology in epilepsy: the views of patients, caregivers and healthcare professionals

Elisa Bruno^a, Sara Simblett^b, Alexandra Lang^c, Andrea Biondi^a, Clarissa Odoi^b, Andreas Schulze-Bonhage^d, Til Wykes^{b,e}, Mark P Richardson^{a,f}, on behalf of the RADAR-CNS Consortium^g

^a Institute of Psychiatry, Psychology & Neuroscience, Division of Neuroscience, King's College London, 5 Cutcombe Road, London SE5 9RX, UK

^b Institute of Psychiatry, Psychology and Neuroscience, Department of Psychology, King's College London, De Crespigny Park, London SE5 8AF, UK

^c NIHR Mental Health MedTech Co-operative, Division of Psychiatry and Applied Psychology, Faculty of Medicine, Institute of Mental Health, University of Nottingham Innovation Park, Triumph Road, Nottingham NG7 2TU, UK

^d Epilepsy Center, Department Presurgical Diagnostics, Faculty of Medicine, Medical Center, University of Freiburg, Breisacher Strasse 86b, 79110 Freiburg, Germany

^e South London and Maudsley NHS Foundation Trust, London, UK

^f Centre for Epilepsy, King's College Hospital, Denmark Hill, London SE5 9RS, UK

^g www.radar-cns.org

Corresponding author

Professor Mark P Richardson

Maurice Wohl Clinical Neuroscience Institute

5 Cutcombe Road

London SE5 9RX, UK

Tel: (+44) 20 7848 5429

mark.richardson@kcl.ac.uk

Abstract

Purpose: In recent years digital technology and wearable devices applied to seizure detection have progressively become available. In this study we investigated the perspectives of people living with epilepsy (PWE), caregivers (CG) and healthcare professionals (HP). We were interested in their current use of digital technology as well as their willingness to use wearables to monitor seizures. We also explored the role of factors influencing engagement with technology, including demographic and clinical characteristics, data confidentiality, need for technical support and concerns about strain or increased workload.

Methods: An online survey was constructed drawing on previous data collected via focus groups and was distributed via a web-link. Using logistic regression analyses, demographic, clinical and other factors identified to influence engagement with technology were correlated with reported use and willingness to use digital technology and wearables for seizure tracking.

Results: 87 surveys were completed, fifty-two (59.7%) by PWE, 13 (14.4%) by CG and 22 (25.3%) by HP. Responders were familiar with multiple digital technologies, including the internet, smartphones and personal computers and the use of digital services was similar to the UK average. Moreover, age and disease-related factors did not influence access to digital technology. The majority of PWE were willing to use a wearable device for long-term seizure tracking. However, only a limited number of PWE reported current regular use of wearables, and non-users attributed their choice to uncertainty about the usefulness of this technology in epilepsy care. PWE envisaged the possibility of understanding their condition better through wearables and considered, with caution, the option to send automatic emergency calls. Despite concerns around accuracy, data confidentiality and technical support, these factors did not limit PWE's willingness to use digital technology. CG appeared willing to provide support to PWE using wearables and perceived a reduction of their workload and anxiety. HP identified areas of application for digital technologies in their clinical practice, pending an appropriate reorganization of the clinical team to share the burden of data reviewing and handling.

Conclusions: Unlike people suffering from other chronic health conditions, PWE appeared not to be at risk of digital exclusion. This study highlighted a great interest in the use of wearable technology across epilepsy service users, carers and health professionals, which was independent of demographic and clinical factors and outpaced data security and technology usability concerns.

Keywords: epilepsy, wearable technology, stakeholders' view, seizure detection

1. Introduction

Epilepsy is one of the most common neurological disorders, affecting about 0.6% of the population worldwide [1]. It is characterized by recurrent seizures which are typically unprovoked and apparently unpredictable [2]. The management and treatment of epilepsy are mainly guided by the assessment of seizure recurrence and frequency. In routine clinical practice, seizure tracking relies on subjective patient recall and self-reporting, which is known to be extremely unreliable [3]. In the diagnostic setting the gold standard for seizure detection is electroencephalography (EEG), in combination with video monitoring. The EEG equipment is obtrusive and uncomfortable for long term use, and its application in everyday life seizure monitoring is considered unacceptable [4]. The last decade has seen an explosion in the capability of monitoring individuals via sensors built into smartphones or wearable devices. Remote health measurement technologies (RMT), defined as any mobile technology that enables the monitoring of an individual's health status through a remote interface [5], allows a non-invasive and continuous assessment over time in non-traditional healthcare settings [6,7]. Novel applications of mobile technologies include the possibility to record non-EEG signals which may help in measuring seizure-induced clinical manifestations [8]. An objective and continuous collection of information on seizure occurrence, frequency and distribution would guide a more tailored management and inform decisions on treatment optimization. However, the successful adoption of RMT and its implementation in conventional healthcare systems might present challenges. Engagement with target users and acceptability in terms of adoption is key. Information about whether people with epilepsy (PWE) have access to digital services and technology is lacking. Previous studies have suggested that some health conditions may be a barrier to the use of digital technologies with an indication that this may particularly be the case in chronic conditions [9]. Robotham et al. [9] found that demographic variables, in particular age, may further explain some of the reasons for inequalities in use. Costs in terms of concerns about confidentiality and need for technical support have been highlighted as important potential barriers for engagement that need to be balanced against perceived utility [Simblett et al, unpublished]. There is a limited number of investigations exploring the willingness of people living with epilepsy (PWE) to use digital technologies for seizure detection and factors influencing their attitudes [10-12]. This study explores these factors in greater depth. However, it is not just individual users who are important, we also need to know about the likely support they may be offered. Therefore, we included caregivers (CG) and healthcare professionals (HP) working in the epilepsy field and also asked them about their use and willingness to use digital technologies to support someone living with epilepsy. Anticipated concerns about increased workload from previous research [13] were

investigated. The final part of this paper explored features to support the design of acceptable digital RMT in the future.

2. Methods

2.1 Survey instrument

An online survey was constructed drawing on previous data collected via focus groups conducted on the topic (unpublished data) and was reviewed by our patient advisory board who made some suggested changes to the vocabulary and layout of the survey. Respondents were asked about their (a) current use of digital services and devices; (b) their willingness to use digital services and devices, including the benefits and concerns of recording seizures with a device; and (c) more practical information about useful parameters to be monitored, receiving the information from a device and need for technical support (including recharging and upgrading devices). Following this common framework, the questions were specifically adapted for each group (surveys available in Supplementary material).

2.2 Recruitment process

The survey and study procedures were approved by the London - Westminster Research Ethics Committee (16/LO/1513; IRAS project ID 208970). The survey was distributed via a web-link. Participants were recruited via two NHS Trusts (King's College Hospital (KCH) and South London and Maudsley (SLaM) NHS Foundation Trusts), charities (Epilepsy Action, Epilepsy Research UK), other non-NHS organisations (Independence Homes, the Institute of Mental Health at the University of Nottingham, ILAE-British chapter, IBE newsletter) as well as from databases held by King's College London (KCL), KCH and SLaM. Further web links were posted on the RADAR-CNS website (<https://www.radar-cns.org/news-events/we-want-hear-you>), affiliated clinical research groups (MindTech, Institute of Mental Health, University of Nottingham) and related social media channels. Participants had the option to request a paper version of the survey by contacting the recruiting organizations.

2.3 Statistical analysis

After providing a descriptive analysis of the data we carried out specific correlations between variables noted to affect an individual's response to using digital technology and wearable devices, including age. The role of clinical variables, including disease duration, seizure type (convulsive, including patients with associated focal seizures, versus non-convulsive) and seizure frequency was also explored. Similarly, demographic characteristics (age and gender), clinical characteristics (disease duration, seizure type and seizure frequency) and factors identified to influence engagement, including confidentiality and need for technical support were correlated with the reported willingness to use digital technology and wearables for seizure tracking. Quantitative data

were processed using logistic regression analyses in STATA version 14.0 (StataCorp, College Station, TX, U.S.A.). We also report relevant quotes from participants, highlighting perceptions about the use and acceptability of digital technology and devices.

3. Results

A total of 213 people clicked on a link to access the survey from April 2017 to September 2017. However only 87 (40.8%) gave consent and completed the whole survey. Fifty-two (59.7%) were PWE, 13 (14.4%) CG and 22 (25.3%) HP.

3.1 Sample characteristics

General demographic characteristics of the participants are reported in table 1.

3.1.1 People with epilepsy

The majority of PWE were aged under 40 and were women. Clinical characteristics are summarized in table 2.

3.1.2 Caregivers

CG had been taking care of PWE for 6.0 ± 4.2 years on average (range 1-13). The majority (84.6%) were unpaid and three (23.1%) had received formal training for their role. Eight (61.5%) were taking care of children with epilepsy and five (38.5%) of adults with epilepsy.

3.1.3 Healthcare professionals

Eleven HP (50.0%) were doctors (ten neurologists and one psychiatrist), seven (31.9%) epilepsy nurses, two (9.1%) service managers, one (4.5%) learning disability nurse and one (4.5%) medical student. The mean number of patients under the care of this group was 158 (± 38.3) and the mean years of experience in the field was 8.4 years (± 5.2 , range 1-20). The majority (63.6%), worked in services for adults, six (27.3%) in services for children and two (9.1%) in both.

3.2 Current use of digital services and devices

The current experience with technology reported by PWE and CG is illustrated in figure 1.

Smartphones, internet, wi-fi and personal computers were widely used among these groups and 95.4% of our sample had experience with multiple technologies. Smartwatches were less well used and were not employed by any CG. When specifically asked about the use of wearable devices, thirty (57.7%) PWE did not own any wearable. The reasons were mainly uncertainty about their usefulness (21.1%, device cost (9.6%), availability (7.7%), appearance (3.8%) and burden/comfort (1.9%). Nevertheless, 19/30 (63.3%) were interested in wearables and had been thinking about purchasing one. Of the 22 (42.3%) PWE who already owned one, 20 (38.5%) were using it regularly. These wearables were mainly used for exercise tracking and general health monitoring but there was a

range of other uses (see figure 2). Among the device features and functionality influencing the choice of the device they owned (figure 3) the similarity to a normal watch, the possibility to track movement, heart rate (HR) and app features were the most important. Other optional monitoring such as sweating or body temperature or being waterproof was less influential on their choice. Only three (23.1%) CG reported that they were taking care of someone using a wearable device regularly, and eight (61.5%) reported that they were taking care of PWE (children and adults) who were thinking about using a wearable. All the HP group were familiar with at least one digital service such as online guidelines (Microguide, upto date), calculation (MedCalc), prescribing/dosing (BNF or similar) and communication (NHS.net, WhatsApp) apps. Forty-five percent of HPs used smartphone apps with their patients, mainly to assist with condition management. Although HPs felt that data from wearables might be useful to enrich their understanding of a patient's health state in between consultations (68.2%) and adherence to medications (50.0%), 40.0% admitted that this information was rarely or never used or discussed in the clinic during the consultations. Half the group had counselled patients on the use of technology and had specifically recommended bed alarms and smartphones or smartwatch apps to help with medication compliance and seizure reporting (e.g. e-diaries).

3.2.1 Factors influencing the current use of digital technology and wearable devices

The use of digital services by PWE and CG was unrelated to participants' age ($p=0.8$) and gender ($p=0.7$). For PWE, the current use of wearable devices was unrelated to epilepsy duration ($p=0.2$), seizure type ($p=0.2$) or frequency ($p=0.5$).

3.3 Willingness to use digital technology and wearable devices

The majority of PWE (80.0%) were willing to use a wearable device for seizure tracking. When asked what type of device would be acceptable for seizure recording/detection in the medium term (weeks) and long term (years), the majority (>69.0%) in each group indicated either a smartphone or a smartwatch (figure 4). A plain wristband (with no watch face), a ring-styled wearable or a sensor under the mattress were additional options for PWE and HP. Headbands and small EEG electrodes were less favoured:

PWE10: "I would be willing to wear some form of EEG if in a private setting. I would therefore not be able to wear this for most of the day, or on a regular schedule"

Comments related to the device being discreet were provided by each group.

PWE21: "I feel it's important that any wearable devices look as 'normal' as possible."

Speaking from personal experience, they can be big, bulky, uncomfortable and an eyesore. It is important to feel dignified, which can be difficult enough during a seizure, let alone when someone drapes a huge buzzer around your neck!"

CG05: *"They need to be non-stigmatising"*

HP12: *"Any device developed must fit in with the current fashion, people don't want to wear devices that make them stand out as having a disability"*

HP19: *"It needs to be non-intrusive"*

Forty-eight (92.3%) PWE reported that they would be willing to use a wearable to monitor seizures for as long as necessary to get an accurate measurement and two (3.7%) for many months.

3.3.1 Factors influencing the willingness to use wearable devices for seizure tracking

For PWE, age, gender, epilepsy duration and seizure type and frequency did not influence the willingness to use any of the device options provided ($p>0.05$).

3.4 Benefits of recording seizures on a device

When asked to rank the greatest benefit of having seizures recorded, PWE prioritised:

- i. having the information for their own knowledge (59.6%)

PWE10: *"...I would like some way to keep track of [...] frequent symptoms and understanding their mechanism and any potential patterns or prompts, ideally in way beyond simply timing them"*

PWE11: *"I am never sure how many seizures I really have so anything to monitor them would be helpful"*

- ii. being able to share the information with their doctor (48.1%)

PWE44: *"It would be beneficial to the individual also real time information for healthcare professionals"*

- iii. having a device that alerts relatives when you have a seizure (36.5%)

PWE13: *"I think it is something that is really needed for people like me who live alone and are very active doing outdoor activities alone or even for people going out on hikes etc. alone. For me, this will lessen my concerns and anxiety"*

Less preferable options were: having a device that can alert medical services (26.9%), having the information available to discuss with your employer (19.2%), having the information available to discuss with welfare benefits services (15.4%):

PWE18: *“I am interested in the health and safety benefits to prove to work that I am not a hazard”*

3.5 Concerns about using digital technology and wearable devices

3.5.1 Confidentiality

When asked about information and data confidentiality, 31 PWE (59.6%) reported concerns about the information not being confidential with nearly half stating specific concerns about privacy, a third for the lack of control over the information and just one quarter because of potential negative effects on their work or their ability to drive. Only four CG (30.8%) reported concerns about the information not being confidential, three about the lack of control over the information and one about potential negative effect on their work.

3.5.1.1 Correlations between confidentiality and the willingness to use wearable devices for seizure tracking

For both PWE and CG, age ($p=0.3$), gender ($p=0.3$) and current use of digital technology ($p=0.4$) did not impact on concerns about data confidentiality. Moreover, for PWE, concerns about confidentiality did not influence their willingness to use wearable devices ($p=0.7$).

3.5.2 Need for technical support

Only a small proportion of PWE (28.8%) considered technical support unnecessary. PWE (48.0%) and CG (53.8%) preferred technical support to be provided in a written document or video tutorial, while HP favoured person to person training (63.6%). The majority of PWE (59.6%) would accept to recharge the device once a day and to upgrade the apps once a week (48.1%) or monthly (30.8%). CG (69.2%) would be keen to assist PWE during these procedures.

3.5.2.1 Correlations between need of technical support and the willingness to use wearable devices for seizure tracking

For both PWE and CG, age ($p=0.1$), gender ($p=0.2$) and current use of digital technology ($p=0.1$) did not influence the need for technical support. Of note, PWE currently using a wearable device reported less need for support, although this trend was not statistically significant ($p=0.09$). The need for technical support did not influence PWE's willingness to use wearable devices ($p=0.7$).

3.5.3 Strain or burden of workload

CGs responded that the decision of PWE to wear a device to monitor seizures would reduce their strain/workload as this would (i) provide valuable and helpful information to identify seizures or

triggers, (ii) give warnings, (iii) reduce anxiety and (iv) represent a potentially accurate and objective tool to help with communication with the healthcare system as compared to subjective reporting:

CG05: *“Reduce worry for carer and increase the independence for person with epilepsy”*

CG11: *“If it told me when he was having a seizure we would not have to constantly watch him to record seizures. I would not have to worry if my timing was accurate as it would be accurately recorded as would his heart rate and if a trip to hospital was needed you have an accurate picture of what happened to help the health professionals. It may also help with an understanding of when these seizures happen and why”*

HPs believed that digital devices could help with patients’ management (68.2%), especially at specific decision points such as treatment initiation/adjustment and diagnosis (providing contextual data), as well as helping patients self-management (63.3%). However, half reported a perceived increase in workload related to the time required for reviewing data and to manage patients’ anxiety about their data. HPs identify the epilepsy nurse as the most appropriate figure to deal with wearable technology data within the epilepsy team:

HP12: *“They are closer to the patient's everyday needs than the neurologist”*

HP19: *“Easiest to access for patient”*

HP22: *“I am (epilepsy nurse) the first point of contact for patients when their epilepsy is not under control, this data will be useful in making planned changes to treatment before the next planned appointment”.*

3.6 Designing acceptable technology

3.6.1 Measurement parameters

When provided with a list of parameters they would considered more useful to help track seizures in the long term (figure 5), all groups selected body movements, heart rate, breathing rate and sleep quality. The majority of PWE favoured multiple parameters if measured simultaneously through the same device:

PWE07: *“A device that monitored heart rate, temperature and menstrual cycle. I have learnt a lot about my triggers over the years from gathering this kind of information”*

PWE42: *“I currently track my menstrual cycle and daily basal body temperature to gather information and regularly check my heart and stress rate using various apps on my smartphone but I feel like the technology is there to be able to track all these things but it needs bringing together in a single device”.*

Less preferable options were location monitors such as GPS, how many time the smartphone is used and voice quality. CG appeared to be less in favour of mood, concentration, attention and memory, while HP were less interested in monitoring skin temperature and environmental factors than PWE. Further desirable features for PWE were stress levels, medication taken, fluid intake, alcohol drinking and oxygen saturation while HP suggested mental state, emotion, stress, blood sugar and observations made by family and friends.

One of the participants in the PWE group expressed the need to extend seizure detection to different seizure types:

PWE52: "The majority of seizure detection devices available focus on tonic-clonic seizures. The majority of my seizures are complex partial seizures and there is very little research in this area. These are the seizures when I feel most vulnerable and are the hardest to control through medication. A greater focus on these would be ideal"

3.6.2 Data accessibility and use

Having the information constantly sent to a computer was preferred by PWE (55.8%) and CG (53.8%) rather than the option of having the information stored in the device and then downloaded onto a computer (38.4% PWE and 23.1% CG). PWE valued the possibility to receive real time feedbacks from the device (46.1%) and were less in favour of a device feature which triggered alarms (19.2%), alerting care providers (11.5%) or relatives, caregivers or friends (7.7%). Conversely, CG were in favour of a device able to trigger an alarm (61.5%) or able to send the information collected immediately to the doctor (53.8%).

The data collected by wearable technologies would be mainly used by HP to assess seizures/post-seizure events (40.9%). Other options included in preparation for a consultation with a patient (36.4%), during consultation with a patient (36.4%) and in between consultations (27.3%). Having the information available during the consultation through direct access to data on the device and having the information available automatically via a secure patient portal were considered better options compared to having the information available at the patients' discretion or via notification when the system detects a change in patient health state.

4. Discussion

In recent years wearable solutions applied to seizure detection have progressively become available. This study aimed to assess PWE access to digital and wearable technology and to identify factors influencing acceptability of digital tools in epilepsy care. We also explored whether PWE and those that support them, including CG and HP, are concerned with similar potential barriers and

facilitators to engagement, including factors already identified to influence engagement: confidentiality, need for technical support and concerns about strain or increased workload. Although generalizability might be limited, our results reflect the view of a population who might benefit from the use of this technology: PWE with active, refractory seizures (mostly TC); CG of children (more vulnerable and more likely represented by caregivers); HP with years of experience in the epilepsy services. We are aware that the limited number of CG and HP taking part in this survey and more data from these groups are needed to better characterize their views.

4.1 Current use of digital technology and wearable devices

Our sample's access and familiarity with multiple digital technologies was high. PWE access to the internet (92.3%) was similar to the UK average (87.9% in 2016) [14] and the prevalence of smartphone ownership (85.6%) was also similar to the national average (88.0%) [15]. In contrast with people suffering from other chronic health conditions [9], PWE seemed to have a lower risk of digital exclusion. Furthermore, age and other factors did not influence their access to digital technology. Nevertheless, these findings should be considered with caution. Although an option to access a paper version was provided, the survey was advertised online, therefore PWE who are more familiar with digital technology might have had easier access to the survey and a higher chance of being enrolled.

Compared to the access to the internet and smartphones, the use of wearables appeared more limited and only 38.3% of PWE owned a smartwatch. National statistics on wearable devices ownership are not available. In our sample, wearables were mainly employed for exercise and general health tracking, reflecting the use of this technology in the general population and impacting on favourite features ("movement" and "HR") ranking. The use of wearables for epilepsy monitoring was reported by a minority of participants and responders disclosed some uncertainty about the usefulness, application and availability of this technology to their care. The lack of evidence-based recommendation regulating the use of wearables in epilepsy care may explain this result as well as HPs' reluctance to recommend wearables.

4.2 Willingness and factors influencing the use of digital technology and wearable devices

Despite only a limited proportion of our PWE (38.5%) reporting a regular use of wearables, the majority (80.0%) expressed an interest in using a device, confirming the presence of a dissociation between the small user group and a potential larger user group reported by previous investigations [10,11]. Devices commonly used in daily life by healthy individuals, such as smartphones and smartwatches, were indicated as the most acceptable for seizure detection, a finding that appeared

in line with other studies [10,12]. Conversely, less common and less discreet solutions (headband, EEG electrodes) were perceived as more stigmatizing in a daily-life setting, as clearly stated by participants in the free text comments. Overall, PWE appeared in favour of a long-term use of wearables, as emphasized in a similar study [11], and our patients were willing to use wearables as long as necessary to get accurate measurements. This answer and the uncertainty about the usefulness of wearables expressed by current non-users suggest that accuracy represents a key concern for patients.

A majority of PWE manifested concerns related to data safety, especially for the consequences that privacy breach could have on daily life and restriction of freedom, including driving, work and insurance. Despite its importance, data security has been rarely addressed in previous investigation in PWE and only one study considered confidentiality important [10].

The need for technical support appeared minimal in our population and the familiarity with digital technology appeared to positively influence user's independence.

Of note, demographic and clinical factors did not influence PWE's willingness to use wearables, including concerns related to data confidentiality and need for technical support.

4.3 Benefit and concerns about using digital services and devices

PWE considered the possibility to acquire information that could help improve their knowledge of their condition as the major benefit of using a wearable device. Contrary to our hypothesis that technology may increase strain or workload burden, CG considered the wearable solutions as a tool to alleviate the anxiety related to the responsibility of being constantly monitoring PWE and to improve communication with healthcare providers via objective reporting.

HP seemed keen to integrate wearable technology data into specific decision points although they identified a data handling and reviewing burden. Novel technologies should be endorsed by dedicated figures within the epilepsy care team, such as the epilepsy nurse, as also pointed-out in a recent review on RMT adoption into primary care [13].

4.4 Designing acceptable technology

4.4.1 Measurement parameters

Apparently in contrast with the preferred small form factor, PWE expressed the need to incorporate and integrate many measurements (active and passive) and sensors into a single device. PWE's experience of a variety of seizure-related physiological manifestations and precipitants informed their selection and was also reflected in the overlapping HPs' preferences. Wearable application was not exclusively confined to seizure detection rather extended to seizure risk assessment, through

combining physiological and contextual information. As underlined before [16], the potential role of less well recognized parameters such as sweating and voice quality was not so much valued. Conversely, stress was suggested as an additional feature. In contrast with the view of PWE and HP, CG were less interested in tracking mood, concentration, attention and memory. We can speculate that our sample of CG mainly dealing with children might have been exposed to less significant behavioural and cognitive alterations as compared to adult populations.

4.4.2 Data accessibility and use

PWE mainly opted for direct and automatic data streaming and appeared willing to share the information with their doctors and to receive direct feedback. Surprisingly, only a minority (26.9%) considered beneficial the option to send alarms, in contrast with previous research reporting higher proportions (68.7% [10], >50% [12]). Although we cannot exclude the role of sample characteristics and methodology and despite our survey not specifically addressing this topic, we believe that the limited interest in sending alarms may reflect a degree of uncertainty about data accuracy, the possibility to receive false alarms [11, 12] and probably the awareness that assistance and emergency call are not required for all seizures. The choice of alerting relatives for immediate support rather than doctors also pointed towards the same direction and reflected the view provided by other studies [10, 11]. In addition, we cannot exclude that PWE perceived device-generated warnings as an additional “uncontrolled” factor potentially increasing the fear related to seizure unpredictability [17-19] mentioned by one subject in our survey PWE18: *“I lived in fear of when the next one would be”*.

In contrast with this, CG would prefer the device to trigger an alarm and alert doctors, confirming previous findings [17].

4.5 Unmet needs

Although only mentioned by a minority in our sample, the need for research focused on non-convulsive seizures and seizures with preserved awareness appeared extremely relevant and echoed similar views expressed for both seizure detection [11, 16] and prediction [4]. Despite equally affecting PWE’s life, seizures considered as less severe and less life-threatening have not received adequate attention and identifying seizure types that do not exhibit limb movements still represents a challenge [20].

5. Conclusions

Wearables currently represent a field of investigation not yet incorporated into routine epilepsy care. The successful implementation of digital tools cannot disregard accessibility and acceptability

of the technology to users or their engagement with it. Our survey indicated that PWE seem to have a good access to digital technology and are interested in the long-term use of preferably small, commonly used, multimodal wearable devices. However, data accuracy was a key concern for users and this should be taken into account in the design of acceptable devices for seizure detection. Despite concerns around data confidentiality and technical support, these factors were not limiting PWE's willingness to use the technology. When a broad range of potential use-cases was presented, PWE favoured the possibility to acquire information in the attempt to mitigate seizure unpredictability over the option to generate automated emergency calls, which is currently considered the major benefit of RMT application in epilepsy. Many encouraging messages emerged from this work, underlining the interest in research exploring the role of wearables in epilepsy. Nevertheless, in order to meet service users' needs and have an impact on PWE wellbeing, further efforts are needed to incorporate multiple measurements into a single device and to improve the capability to detect a wider range of seizure types.

Funding

The RADAR-CNS project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 115902. This Joint Undertaking receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA, www.imi.europa.eu.

Acknowledgement

We would like to thank Jose Ferrao and Ashley Polhemus from MSD IT Prague for their support in the adaptation of the surveys.

Til Wykes acknowledges the support of the NIHR Biomedical Research Centre at South London and Maudsley NHS Foundation Trust and King's College London and her NIHR Senior Investigator award.

Disclosure

MR is supported by the MRC Centre for Neurodevelopmental Disorders (MR/N026063/1), the EPSRC Centre for Predictive Modelling in Healthcare (EP/N014391/1) and an MRC Programme Grant (MR/K013998/1). MR and TW are supported by the NIHR Biomedical Research Centre at the South London and Maudsley NHS Foundation Trust. TW also acknowledges the support of her NIHR Senior Investigator Award. This is an independent study. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

This communication reflects the views of the RADAR-CNS consortium and neither IMI nor the European Union and EFPIA are liable for any use that may be made of the information contained herein. The authors declare no financial or other conflict of interest. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

References

- [1] Ngugi AK, Bottomley C, Kleinschmidt I, Sander JW, Newton CR. Estimation of the burden of active and life-time epilepsy: a meta-analytic approach. *Epilepsia* 2010; 51:883–890.
- [2] Shorvon S, Guerrini R, Cook M and Lhatoo S. *Oxford Textbook of Epilepsy and Epileptic Seizures*. Oxford University Press Dec 2012.
- [3] Cook MJ, O'Brien TJ, Berkovic SF, Murphy M, Morokoff A, Fabinyi G, et al. Prediction of seizure likelihood with a long-term, implanted seizure advisory system in patients with drug-resistant epilepsy: A first-in-man study. *Lancet Neurol* 2013;12:563–571.
- [4] Schulze-Bonhage A, Sales F, Wagner K, Teotonio R, Carius A, Schelle A, et al. Views of patients with epilepsy on seizure prediction devices. *Epilepsy & behavior* 2010; 18.4: 388-396.
- [5] Sarasohn-Kahn J. *The connected patient: charting the vital signs of remote health monitoring*. California: HealthCare Foundation; 2011.
- [6] Vegesna, A, Tran M, Angelaccio, M, Arcona, S. Remote patient monitoring via non-invasive digital technologies: a systematic review. *Telemedicine and e-Health* 2017; 23(1), 3-17.
- [7] Ramgopal S, Thome-Souza S, Jackson M, Kadish N.S, Fernandez I.S, Klehm J, et al. Seizure detection, seizure prediction, and closed-loop warning systems in epilepsy. *Epilepsy Behav* 2014;291-307.
- [8] Ulate-Campos A, Coughlin F, Gaínza-Lein M, Sánchez Fernández I, Pearl PL, Loddenkemper T. Automated seizure detection systems and their effectiveness for each type of seizure. *Seizure* 2016;40:88–101
- [9] Robotham D, Satkunanathan S, Doughty L, Wykes T. Do We Still Have a Digital Divide in Mental Health? A Five-Year Survey Follow-up. *J Med Internet Res*. 2016;18:e309.
- [10] Hoppe C, Feldmann M, Blachut B, Surges R, Elger CE, & Helmstaedter C. Novel techniques for automated seizure registration: patients' wants and needs. *Epilepsy & Behavior* 2015; 52, 1-7.
- [11] Quiroga Diego F. Tovar, Britton WB, Wirrell CE. Patient and caregiver view on seizure detection devices: A survey study. *Seizure-European Journal of Epilepsy* 2016; 41: 179-181.

- [12] Van de Vel A, Smets K, Wouters K, Ceulemans B. Automated non-EEG based seizure detection: Do users have a say?. *Epilepsy & Behavior* 2016; 62: 121-128.
- [13] Davis MM, Freeman M, Kaye J, Vuckovic N & Buckley DI. A systematic review of clinician and staff views on the acceptability of incorporating remote monitoring technology into primary care. *Telemedicine and e-Health* 2014; 20.5: 428-438.
- [14] Office for National Statistics. [2016-08-18]. Internet users in the UK: 2016.
<https://www.ons.gov.uk/businessindustryandtrade/itandinternetindustry/bulletins/internetusers/2016> webcite.
- [15] Wike R & Simmons K. Global Support for Principle of Free Expression, but Opposition to Some Forms of Speech. Pew Research Center, 2015
<http://www.pewglobal.org/2015/11/18/global-support-for-principle-of-free-expression-but-opposition-to-some-forms-of-speech/>
- [16] Patel AD, Moss R, Rust SW, Patterson J, Strouse R, Gedela S, et al. Patient-centered design criteria for wearable seizure detection devices. *Epilepsy & Behavior* 2016; 64: 116-121.
- [17] Arthus S, Zaveri HP, Frei MG, Osorio I. Patient and caregiver perspectives on seizure prediction. *Epilepsy & Behavior* 2010; 19.3: 474-477.
- [18] Mormann F, Elger CE, Lehnertz K. Seizure anticipation: from algorithms to clinical practice. *Curr Opin Neurol* 2006;19:187–93.
- [19] Schelter B, Winterhalder M, Feldwisch Genannt Drentrup H, et al. Seizure prediction: the impact of long prediction horizons. *Epilepsy Res* 2007;73:213–7.
- [20] Bidwell J, Khuwatsamrit T, Askew B, Ehrenberg JA, Helmers S. Seizure reporting technologies for epilepsy treatment: A review of clinical information needs and supporting technologies. *Seizure-European Journal of Epilepsy* 2015; 32: 109-117.

Table 1. Demographic characteristics of the participants (N=87)

Characteristics	PWE (N, %)	Caregivers (N, %)	Healthcare professionals (N, %)
Number	52	13	22
Age group			
Under 20	2 (3.8)	0 (0.0)	0 (0.0)
20-29	9 (17.3)	2 (15.3)	2 (9.1)
30-39	25 (48.1)	4 (30.8)	10 (45.4)
40-49	5 (9.6)	4 (30.8)	4 (18.2)
50-59	11 (21.2)	3 (23.1)	5 (22.7)
60-69	0 (0.0)	0 (0.0)	1 (4.6)
Gender			
Female	43 (82.7)	12 (92.3)	14 (63.6)
Employment			
Full-time	20 (38.5)	6 (46.1)	21 (95.5)
Part-time	10 (19.2)	4 (30.8)	0 (0.0)
Unemployed	20 (38.5)	3 (23.1)	1 (4.5)
Retired	2 (3.8)	0 (0.0)	0 (0.0)

PWE: people with epilepsy

Table 2. Clinical characteristics of PWE (people with epilepsy, N=52)

Clinical characteristics	(N, %)
Disease duration (years) mean±SD	16.7±13.8
Seizure frequency (seizure/month) median (range)	2 (0-210)
Seizure type (last two years)	
Tonic-clonic	33 (63.5)
Focal	16 (30.7)
Tonic	25 (48.1)
Myoclonic	2 (3.8)
Absence	9 (17.3)
None	2 (3.8)
Number of AEDs	
One	17 (32.7)
Two	20 (38.5)
Three or more	13 (25.0)
None	2 (3.8)
Non-pharmacological treatment	
Epilepsy surgery	4 (7.7)
Vagus nerve stimulation	4 (7.7)
Deep brain stimulation	1 (1.9)
Time to full recovery after a seizure	
≤1hour	21 (40.4)
>1 hour and <1 day	20 (36.5)
Many days	11 (21.1)

AEDs: anti-epileptic drugs, SD: standard deviation

Figures legend

Figure 1. Which of the following technologies do you currently use?

PWE: people with epilepsy

Figure 2. For what purposes do you use your wearable device?

Figure 3. What features influenced your wearable device selection?

GPS: global positioning system; HR: heart rate.

Figure 4. Which of the following do you think would be acceptable to use for detecting and recording seizures?

PWE: people with epilepsy

Figure 5. Which of the following would you agree could be useful to be recorded over a long period of time (at least a year) to help to keep track of seizures?

PWE: people with epilepsy